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Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions

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Abstract *Purpose:* The aim of this study is to examine family members' experiences of end-of-life decision-making processes in Norwegian intensive care units (ICUs) to ascertain the degree to which they felt included in the decision-making process and whether they received necessary information. Were they asked about the patient's preferences, and how did they view their role as family members in the decision-making process? *Methods:* A constructivist interpretive approach to the grounded theory method of qualitative research was employed with interviews of 27 bereaved family members of former ICU patients 3–12 months after the patient's death. *Results:* The core finding is that relatives want a more active role in end-of-life decision-making in order to communicate the patient's wishes. However, many consider their role to be unclear, and few study participants experienced shared decision-making. The clinician's expression "wait and see" hides and delays the communication of honest and clear information. When physicians finally address their decision, there is no time for family participation. Our results also indicate that nurses should be more involved in family–physician communication. *Conclusions:* Families are uncertain whether or how they can participate in the decision-making process. They need unambiguous communication and honest information to be able to take part in the decision-making process. We suggest that clinicians in Norwegian ICUs need more training in the knowledge and skills of effective communication with families of dying patients.

Keywords Intensive care · End of life · Decision-making · Communication · Family members

Introduction

Most deaths in intensive care units (ICUs) take place after a decision is made to limit or withdraw medical treatment. Questions regarding the level and aim of treatment form an important part of day-to-day activities in ICUs [1]. According to Norwegian legislation, healthcare decisions involving serious interventions should be based on informed consent [2]. However, ICU patients generally have impaired cognition and are unable to decide for themselves; therefore, they depend on surrogates to make decisions on their behalf [3]. Traditionally, and due to legislation, families in European countries have been less involved in end-of-life decisions than in the USA [4–6].

In Norway, legislation gives the physicians in collaboration with other clinicians (physicians and nurses) the final decision-making authority [2]. The Patients' Rights Act (1, §4.6) states that, in order to determine patients' wishes, if possible information shall be obtained from next of kin about the patient's presumed consent [2]. Involving family members as informants and spokespersons for the patient is a challenging process. To participate in the decision-making process, they need detailed information and thorough comprehension of the patient's prognosis. Moreover, relatives do not always know the patient's preferences and may have difficulty discriminating between the patient's values and their own interests [7, 8]. It may also be difficult for them to understand the complexity and severity of the condition in an emotionally demanding situation [9]. Providing family members with appropriate information over time increases their ability to participate in the decision-making process [1, 10–12].

A European consensus committee advocates a shared approach to end-of-life decisions, involving both the caregiver team and patient surrogates. The family's role is to communicate the patient's preferences [7, 13]. However, according to Scandinavian studies, physicians consider limiting intensive care treatment to be a medical decision in which they are the principal arbiter [14–16], and this often occurs without including nurses [17, 18] or making ethical reflections explicit [16]. Moreover, some physicians are reluctant to discuss ICU goals and methods with relatives when the patient is incompetent [19]. Written advanced directives are not common [19] and have no legal authority in Norway.

The aim of this study is to examine relatives' experience of the end-of-life decision-making process in Norwegian ICUs. To what degree did they feel included? Did they receive necessary information? Were they asked about the patient's preferences, and how did they see their role as a family member in the decision-making process?

Materials and methods

Study design

A constructivist interpretive approach to the grounded theory method of qualitative research was employed [20], with interviews of 27 bereaved family members of 21 ICU patients who died after a decision to withhold or

Table 1 Participant demography and relation to former intensive care unit patients

No.	Patient[a]	Age (years)	Participant relation	Age (years)	Months from patient death to interview[b]
1	Male	61	Wife	59	12
2	Male	55	Wife	54	8
3	Female	68	Daughter	36	7
			Daughter	42	
4	Male	57	Mother	80	7
		57	Brother	51	
5	Female	62	Husband	76	8
6	Female	59	Daughter	27	12
7	Male	35	Wife	33	12
8	Male	80	Wife	79	11
			Daughter	48	
9	Male	68	Wife	54	5
10	Male	33	Mother	50	3
11	Male	45	Wife	46	12
			Sister	42	
			Sister	41	
			Daughter	20	
12	Female	77	Husband	78	10
13	Female	81	Son	54	6
14	Male	40	Wife	39	11
15	Female	38	Husband	34	9
16	Female	74	Daughter	48	11
17	Male	75	Daughter	34	6
18	Female	85	Son	51	10
19	Male	67	Brother	61	6
20	Male	68	Daughter	45	11
21	Male	55	Wife	60	11

Study participants: 20 female, 7 male. Age between 20 and 80 years, average age 49.7 years

[a] Patients: 8 female, 13 male. Age between 33 and 85 years, average age 61 years

[b] Average time from patient death to family interview: 9 months

withdraw life support (Table 1). The interviews were conducted between May 2008 and November 2009.

Grounded theory seeks to describe and understand social and structural processes in social settings. The goal of basic grounded theory research is to develop theory from data collected by the researcher. In this approach, the researcher is more a distant observer. A constructivist approach recognizes the interaction between the researcher and the participants and sees both data and analyses as created from shared experiences and relationships with participants [20].

The study was approved by the Regional Committee for Medical and Health Research Ethics, the Norwegian Social Science Data Services (NSD), and subsequently by the participating ICUs.

Sample and data collection

Three university hospitals and one district hospital participated in the study. Hospitals were selected based on their ICU size (>8 beds) and type of unit (general ICU). A sample of family members was selected from each ICU's patient database by local research coordinators. Inclusion criteria were age greater than 18 years for both the patient and the family member. The decision to withdraw treatment was documented in the patient record. Families who had been asked to consent to organ donation were excluded. Information on the study and an invitation to participate were sent from the local research coordinators to the selected family members. Those who elected to participate returned the written consent in a prepaid envelope addressed to one of the researchers (R.L.), who also was the only interviewer. Most interviews took place in the participant's home. Due to long distances, two interviews were conducted via telephone.

Data production and analysis

The methods of data production and analysis are described in detail in Online Resource 1. In brief, the interviews were held within 3–12 months after the patient's death, with an average of 9 months (Table 1). An extensive narrative was elicited beginning with a narrative-inducing question: "Can you tell me what happened?" The second phase of the interview reflected the ordering of the themes presented by the interviewee. However, the interviewer also used an interview guide as a background tool to ensure that relevant topics were covered in the dialog. The interviews lasted about 1 h, and were digitally recorded and transcribed verbatim. The data were organized using NVivo, a software package that facilitates sorting and coding.

The goal of the analysis was to gain an understanding of the family members' roles and reactions during interactions with physicians and nurses during end-of-life discussions in the ICU. First, individual interviews were thoroughly analyzed by two researchers (G.F.L. and R.L.), with relevant episodes then isolated and arranged into themes [21]. Using the interpretive grounded theory method, the themes were coded and named using various terms [20]. The concepts and the relationships between concepts emerged within single interviews and between interviews, although the emphasis remained on the whole, as in a hermeneutic circle. In organizing the data, initial codes were chosen to facilitate analysis. The cases were then labeled based on the participant's experience of inclusion in the decision-making process and then divided into two groups (Fig. 1). The underlying assumptions of the different cases were compared. A common key concept emerged: "wait and see."

Results

Most participants were not included in end-of-life decisions (Fig. 1). A few were included to some extent and experienced shared decision-making. The key characteristics of the experiences varied, as shown in Fig. 1. The expression "wait and see" was experienced by participants from both groups, and it was related to communication with both physicians and nurses (see more quotations from participants in Online Resource 2). Five subthemes demonstrate the variety in this main concept:

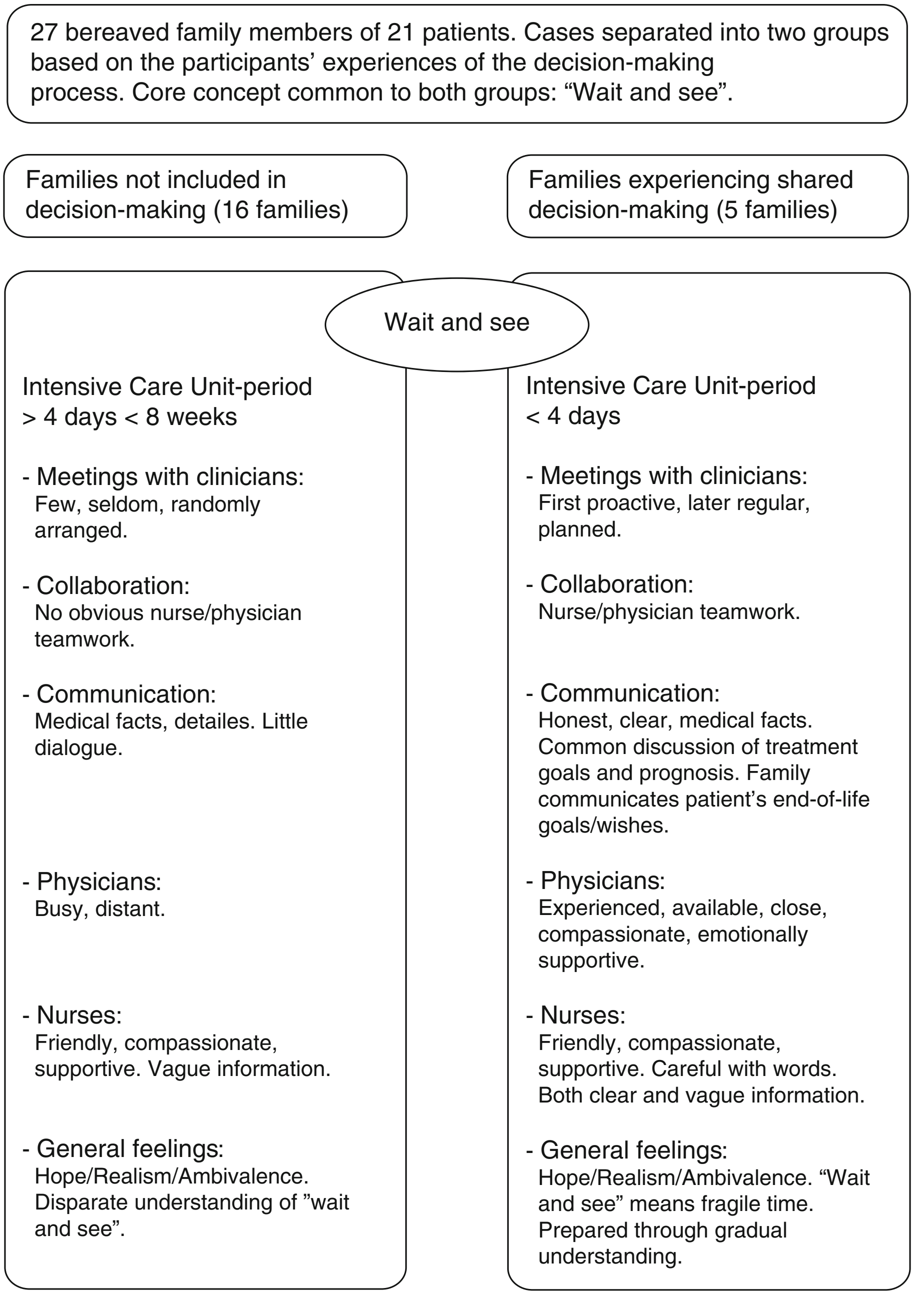
- Unavailability
- Ambivalence
- Disparate comprehension
- Delayed communication
- Shared decision-making

"Wait and see"

Unavailability

Firstly, the expression "wait and see" may be viewed as a key concept describing a study participant's experience of inadequate communication with ICU clinicians. Few participants experienced regular physician communication. The physicians often seemed busy, did not keep appointments, and left the family waiting for hours. When family members did succeed in meeting a doctor, they found they were rarely given enough time for proper dialog. One daughter, who was with her father for 1 week in the ICU, states: "There was little… very little communication. The only time we talked with doctors was that time the two doctors sat down with us. We had no contact apart from what we heard from the discussion

Fig. 1 Results



when they arrived on their rounds" (no. 8). The communication often focused on measurable details, such as oxygen saturation, blood pressure or test results. Many families felt that they needed more frequent discussions concerning the perspectives of the treatment. One family member said: "There were… lots of questions I could ask, but I would not get an answer (from nurses). A doctor had to answer them… But then… then it seems a bit of an uphill path to get information and arrange a meeting with a doctor…" (no. 18). Nurses rarely participated in meetings between families and physicians. Bedside communication focused on everyday issues and the well-being of the patient. Families perceived the nurses as friendly and compassionate, but vague and reluctant to give information.

Ambivalence

Secondly, "wait and see" can be interpreted as an expression of a degree of uncertainty that is intended to protect family members, helping them to maintain hope for recovery. Being near the patient most of the time makes the family form their own ideas about the patient's prognosis. Even if family members recognize some signs indicating that the patient's situation is worsening, they need to maintain some hope for survival. Many found that doctors and nurses took this into account by shielding them. The vague communication with nurses was interpreted as part of this. They reflected upon the concept that this is a difficult balancing act for hospital staff. Sometimes they received clear, realistic information that the situation could go either way. In retrospect, many felt that uncertainty was hidden behind a focus on continued full treatment and the hope for improvement. A wife said that "they never actually said it would not work out, to start with. They had hope, and we clung to it" (no. 9).

Disparate comprehension

Thirdly, "wait and see" can indicate differing viewpoints and perceptions of the clinicians and the family. Several study participants were unsure about what would happen after "waiting and seeing." One participant states: "When he talked to me then, he prepared me for the meeting at the weekend when they would decide what would happen. And there would be a heart specialist and other experts at the meeting" (no. 16). In retrospect, the families realized that "wait and see" was in fact used to convey treatment termination at a given time, unless there were unexpected signs of improvement. Others had previously understood it as meaning that the doctors were uncertain about the outcome. However, several family members felt that the end-of-life discussion after the "wait and see" period was over came up too abruptly.

Delayed communication

Fourthly, the "wait and see" period sometimes delayed the important part of the discussion regarding the decision-making process and made it difficult for the family to recognize their role as surrogates for the patient. Some family members were relieved to discover that the physicians are responsible for decisions, but still had a perception of the importance of their own contribution. One woman, married for more than 30 years, said: "My husband and I were very conscious of wanting to be the closest relatives and part of this was to be confident that the spouse made the best decision" (no. 1). Despite the fact that few patients had previously discussed end-of-life goals within their family, the relatives believed they knew the end-of-life wishes of the patient. They based this on their previous generalized conversations on moral values and end-of-life goals. This carries with it a strong feeling of responsibility to communicate this knowledge to the clinicians. However, few participants were asked if they knew the patient's preferences. Generally, the physicians focused entirely on the clinical details when they announced their decision to withdraw treatment. Several family members, while presuming that the correct decision had been made, would still have preferred greater involvement in the decision-making process. Looking back, one son said: "Her quality of life was not part of the discussion… no, in fact it was not… They should have discussed it with me… that is what I think. It is actually a moral question. It is really difficult" (no. 18). Several family members recall the situation as emotionally charged. Some were left with unanswered questions, leading to doubt about whether the correct decision was made. They were unsure whether they had received all necessary information or if there were other aspects to be considered. Moreover, since termination of care was usually carried out very quickly, they had no time to reflect upon it or express doubts.

Shared decision-making

For a few family members the "wait and see" period worked as a preparation phase for the decision-making process (Fig. 1). These families experienced early family meetings in which clinicians made efforts to establish a relationship and provide the family with emotional support. In later meetings, the patient's preferences were discussed and treatment goals were revised. Nurses sometimes took part in the family meetings. An elderly man who lost his wife said: "In a way, I was prepared by the process which went on continuously, and the talks with those two fantastic professionals. And it was obvious to me that it was her life it was all about, and on the doctor's recommendation I saw no reason to continue the treatment" (no. 12). Other participants also found that the physicians acted as their advisers, inviting them to take part in the final decision.

Discussion

The major finding of this study is that the concept of "wait and see" describes the communication process with families in the participating Norwegian ICUs in various ways. Despite well-documented strategies to prepare families for end-of-life decisions [22–24], the families' perspectives in this study reveal an ineffective and ambiguous communication strategy. This is an area where the data can be interpreted in different ways. The end-of-life decision may seem sudden and unexpected because the family is not mentally prepared. We also know that being in an emotionally charged situation may reduce the family's ability to recognize the physicians' information [22]. However, it can also be considered as an unclear communication process where the reality of the situation is played down.

Some uncertainty in the communication process can probably be related to an interpretation of current legislation on decision-making processes when the patient lacks decision-making capacity [2]. The legislation gives no details as to how and when families should be included in decision-making. Written guidelines on intensive care ethics are not common in Scandinavia [19]. However, a new Norwegian guideline for end-of-life decisions exists, but its implementation is still controversial among physicians, who may be reluctant to change established practice [25]. Our results, nevertheless, show clearly that families experience the usual approach based on vague communication as inappropriate.

"Wait and see" might be a term that physicians use to delineate a period of time to ensure that the withdrawal decision is correct [16, 26]. The process of defining a turning point where treatments are considered futile is ethically challenging [17, 19]. However, the expression "wait and see" is itself elusive, and together with continued full treatment and vague communication, it obscures the severity of the situation, which the time limit is meant to signal [13, 26]. Our study demonstrates that this often resulted in delayed communication with families about adjusting treatment goals, denying them the opportunity to communicate the patient's preferences. Similarly to other studies, this study shows that families need regular meetings with physicians with an appropriate balance between hope for survival and accurate and straightforward information about the illness and the prognosis [27, 28].

When physicians finally raise the end-of-life issue, they seem to have run out of time to include the family. Consistent with other Scandinavian research in this field, most participants in our study were merely told the decision [29, 30]. Hence, they were left with unanswered questions and sometimes doubted the decision. They expected their contribution to the process to be important for the patient; on the other hand, some studies have questioned whether the family is able to communicate the patient's "best interests" with regard to values and quality of life issues and, thereby, protect the patient's autonomy [7, 31, 32]. However, if the voice of the family is supposed to express the patient's wishes, it is important that they be allowed to participate earlier in the decision-making process.

As reported in other studies, nurses seldom took part in end-of-life discussions or in family–physician conferences [17, 33, 34]. Nurses and doctors are, therefore, not utilizing the waiting period properly in order to prepare the family for the final end-of-life decision. A few family members were satisfied with and (to some degree) included in the decision-making process (Fig. 1). The ICU period for these patients was limited to a few days. A possible interpretation is that the patient was expected to die soon at the time of admission to the ICU, and that communication efforts towards families were thus maximized. This first proactive step was laying the groundwork [35] by establishing a relationship and providing the family with emotional support. The next step, as emphasized in other studies and guidelines [22–24, 35, 36], introduced a clearer communication of the prognosis, allowing the family and the clinicians together to revise the initial goals [37]. Nurses were included in the meetings to some degree and used their acquired relationship and knowledge to support the family after the meetings. Consistent with other studies, our results therefore suggest that nurses should engage more in end-of-life situations and contribute to building a team for family support [13, 28, 38]. For these few families who experienced shared decision-making, the "wait-and-see" expression was understood as a fragile time in which they were able to prepare for the final decision to withdraw treatment.

This study is limited by the participants' recollections of the decision-making experience. It is impossible to know if their recollections exactly describe their thoughts and feelings at the time of the decision. Although this qualitative methodology limits generalization, the findings still provide insight into the decision-making process as the families experienced it, and these insights may be transferable to ICUs other than those that participated in the study.

Conclusions

Families of ICU patients express the need for unambiguous communication and clear information about their loved one's condition and prognosis while maintaining hope for recovery. Families often have difficulties understanding and interpreting the information presented. Nurses seldom participate in family conferences, and their communication with families is regarded as vague. The "wait and see" concept functions to conceal the essential question and delay the inevitable choice. Hence, most study participants experienced that the decision-making process took place without their participation. Several families felt that the final decision was hastened. This indicates a lack of attention to patient and family autonomy. The study suggests that physicians and nurses in Norwegian ICUs must discuss how to include families in the decision-making process. The legislation encourages focus on improving communication skills both within the ICU team and between the team and families [39, 40]. Guidelines can be useful in helping clinicians improve these processes.

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Conflict of interest The authors state that there are no conflicts of interest.

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